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POSSIBILITIES OF ACQUIRING COMPETENCIES IN DISEASE MANAGEMENT OF CHILDREN WITH DIABETES MELLITUS

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Abstract. *Diabetes Mellitus is a chronic disease that occurs as a metabolic disorder. Children often have type 1 diabetes, which occurs when pancreas produces very little or no insulin. Type 1 diabetes may negatively affect the normal lifestyle of a child, as well as his/her development, learning results and growth. It is emphasised that it is important for a child to adjust insulin doses based on the consumed food, physical workload and mental strain; therefore, in this case, the child must be aware of diabetes in order to achieve the most optimal health. The subject-matter of research is the opportunities of children with Diabetes Mellitus to acquire competences for the management of their disease. The aim of research is to disclose how children with diabetes acquire competences for the management of their disease and what opportunities they have for such acquisition. The objectives of research are as follows: 1) to discuss what kind of trainings are being provided to children with diabetes in Europe and Lithuania; 2) to disclose which competences help children with diabetes to manage their disease the most based on their experience. Methods of research – theoretical, such as analysis, generalisation and structuring of scientific literature; empirical, such as semi-structured interview used to collect data; and content analysis method used to analyse the obtained research data. 6 children with Diabetes Mellitus participated in this research. The age of the research participants ranged from 10 to 13 years. During the empirical research, it was disclosed that the most important competences of children with diabetes, allowing/enabling them to manage their disease consist of the correct injection of insulin, proper consumption of food and their abilities to manage hypoglycaemia and hyperglycaemia.*
Keywords: *children, competences, Diabetes Mellitus (diabetes), disease management.*

Introduction

Type 1 diabetes is one of the most relevant chronic diseases in the 21st century, which requires special supervision and control in order to avoid such acute or chronic complications as cardiovascular diseases, visual impairment, kidney failure, diabetic coma or even death (Goethals et al., 2017; Goldberg et al., 2017; Melvin, Redahan, Hatunic, & McQuaid, 2019; Sudhanshu, Nair, Godbole, & Reddy, 2019). During the course of diabetes, there is a high blood

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sugar level, which negatively affects the entire metabolism of the body (Batulevičienė, Gaidimauskaitė, & Batulevičius, 2013; Ceriello, Monnier, & Owens, 2019). Diabetes is one of the most prevalent chronic diseases in children; however, children are often diagnosed with it too late, when blood sugar level reaches almost fatal level (Lambrinou, Hansen, & Beulens, 2019).

Data of the International Diabetes Federation (2019) shows that there are 98,200 children under 15 years of age around the world, who were diagnosed with diabetes. For example, in 2019, there were 14,700 new cases of children with diabetes in the USA; 3,500 in Great Britain and 2,600 in Germany (IDF Diabetes atlas, 2019). According to the data obtained by the Institute of Hygiene in Lithuania, 811 cases were registered in Lithuania in 2017, related to type 1 diabetes in children and adolescents, among which less than 400 patients were between 12 and 17 years of age.

Training of children with diabetes was recognised as the primary component necessary for the management of diabetes; meanwhile, the purpose of training is to teach them how to control this disease and to encourage self-monitoring when a person with diabetes is aware of and understands the effects of food, physical activity, tension, medication, etc., as well as knows how to control blood sugar level properly (Bulikaitė & Šeškevičius, 2004; Hawkes, Willi, & Murphy, 2019; Geremia, Fornari, & Tshiedel, 2019). The authors (Beran & Golay, 2017; Mauri et al., 2017) emphasise that teaching must be clear, consistent, professional, high quality and corresponding to the needs of people with diabetes for training because treatment and control depends on it.

The subject-matter of research is the opportunities of children with Diabetes Mellitus to acquire competences for the management of their disease.

The aim of research is to disclose how children with diabetes acquire competences for the management of their disease and what opportunities they have for such acquisition.

The objectives of research are as follows:

1. To discuss what kind of trainings are being provided to children with diabetes in Europe and Lithuania;
2. To disclose which competences help children with diabetes to control this disease the most based on their experience.

Methods of research: theoretical, such as analysis, its comparison and generalisation; empirical, such as semi-structured interview used to collect data; and content analysis method used to analyse the obtained research data.

Questions of survey:

1. What kind of health-related competences do help children to manage their disease?

2. What are the opportunities to acquire competences for the management of this disease in Lithuania? Where do children with diabetes get information about their disease and its management from?

Research methodology

Research methods. Qualitative research type was chosen for the study. According to Žydžiūnaitė & Sabaliauskas (2017), the purpose of a qualitative study is to disclose experiences of children with diabetes, related to the acquisition of competences for the management of their disease, as well as the available opportunities to acquire competences for the management of this disease. The method of a semi-structured interview was used in the study. This article overviews problematic question of the study: "How do you manage or control your disease? Where did you get the necessary information about this disease and its management from?" The obtained data were analysed by using the content analysis method. The qualitative content analysis was performed in the following sequence: the repeated reading of the content of transcribed interview texts, the distinction of meaningful elements in the text analysed, the grouping of the distinguished meaningful elements into categories and sub-categories, integration of the categories/sub-categories into the context of the phenomenon analysed and the description of their analysis (Žydžiūnaitė et al., 2017). P. Mayring (2000) emphasises that content analysis is a valid method for making specific inferences from the analysed text.

The sample of research. A criteria-based sample was used in the study. The respondents were chosen according to the following criteria: 1) children with Diabetes Mellitus; 2) children who suffer from diabetes from the age of 7 to the age of 15; 3) children who found out about the disease at least one year ago. The study was conducted between February and May 2019. The duration of an interview was from 35 to 60 minutes. 6 children with Diabetes Mellitus participated in the qualitative research. The age of research participants ranged from 10 to 13 years. The research was attended by 4 girls and 2 boys.

Ethics of the research. Parents of children who participated in the research, as well as children themselves familiarised with the goal of the research, the interview questions, and the importance of a reasoned reflection on their experience. A parental consent of all research participants was obtained, allowing their children to participate in the research, including the agreement of parents and children to record the interview into a voice recorder. During the research, the following essential principles of research ethics were complied with (Žydžiūnaitė et al., 2017): **a right not to be vulnerable**, i.e. not making any negative impact on their physical, mental and social health; **a right not to be abused** by ensuring that participation of research participants and information provided to them will

not be used against them; **usefulness of the research** – the research participants wilfully agreed to participate in the research because their participation in a specific research makes a positive impact on the development of society and knowledge, as well as the research of new opportunities in Lithuania; **respect for personal dignity** – the research participants were interpreted as independent persons, who were able to control their personal behaviour; every research participant had **a right to make a personal decision whether to participate in the research or not**; **justice** – such factors as the benefit, credulity or compromise was not used in order to involve the "necessary" persons in the research; the participants had an opportunity to ask about the research and receive comprehensive information; the research participants were treated in a respectful and helpful manner; **confidentiality** – the research participants were assured that information provided during the research (the collected qualitative data) will not be disseminated; the unprocessed information will not be available to any person, who is not related to the thesis and, specifically, to the exploratory part of the thesis; **anonymity** – the research participants were assured that their provided accurate personal data will not be published without coordinating such possibility in advance. In order to maintain confidentiality, respondents were encoded in letters A, B, C, D, E and F.

Literature review

Training of children with Diabetes Mellitus in Lithuania and Europe

Training of children with diabetes is important both for the prevention of disease and health economics. Moreover, training of children with diabetes is an important step in the disease management process because the more ill child becomes aware of the disease consequences and acquires the necessary health-related skills, the lower are the consequences of this disease (Swift, Cullen, & Knowles, 2009). The well-prepared training programmes for children with diabetes help them to improve the disease management, which in turn reduce late development and progression of complications (LaManna et al., 2019). For example, the authors Dorresteijn, Kriegsman, and Asssendelft (2012) disclosed that, in Holland, the number of such complications of diabetes as foot ulcers and amputations, has reduced by conducting training programmes; meanwhile, in Lithuania, patients with diabetes are able to manage their disease; thus, experiencing fewer symptoms of disease and other ailments after acquiring the necessary health-related skills (Bartkevičiūtė, Venskaitytė, Samėnienė, & Blaževičienė, 2015).

Such European countries as England, Ireland and Spain organise training programmes for children and adolescents about Diabetes Mellitus, which provide

the necessary health-related skills (Dinneen et al., 2009; Lovell, 2012; Conde-Barreiro et al., 2014).

The primary training programmes in England for children and adolescents with diabetes are *the SKIP course (supporting kids with diabetes in physical activity)* and *X-PERT diabetes education course*. The aforementioned programmes are designed to develop competences of children with diabetes, i.e. to introduce Diabetes Mellitus to them, to provide health-related skills, to promote children and adolescents with diabetes to take care of themselves better (to manage insulin injections, blood sugar level and maintain healthy lifestyle) (Lovell, 2012).

The number of patients with type 1 diabetes in Ireland is increasing the same way it increases in the entire Europe. This trend is visible since 1997. Meanwhile, the number of children and adolescents with diabetes increased by 25%; therefore, such changes encouraged to implement certain strategies and develop various training programmes (Dinneen et al., 2009; Diabetes Ireland, 2017). There is a training programme in Ireland, consisting of three training courses for all people with diabetes, including public concerned. The first one is *a dietitian led X-PERT course,* the second one is *CODE: Community Oriented Diabetes Education* and the third one is *DESMOND: Diabetes Education and Self-Management for Ongoing and Newly Diagnosed.*

The incidence of diabetes also increases in Spain, as well as in Ireland and England; however, the incidence of children and young people under the age of 15 is more visible in Spain (Bareiro et al., 2014; Rica et al., 2017). Therefore, the training programmes about Diabetes Mellitus are oriented to children, young people and adults with diabetes. The main diabetes programmes in Spain are *Diabetes Action*, *Diabetes Education* and *X-PERT programme.* (Conde-Barreiro et al., 2014). Hence, there are many training programmes in Spain, which may be categorised into the following groups: preventive programmes for general public, training programmes to improve health skills and purposeful training programmes, which are performed only in certain areas of Spain (Bareiro et al., 2014; Rica et al., 2017).

Meanwhile, in Lithuania, training of patients with diabetes is emphasised in the scientific literature. V. Bulikaitė and A. Šeškevičius (2004) highlight the relevance of training related to the skills of children with type 1 diabetes because, having learned to monitor blood sugar level, they may prevent hypoglycaemia and hyperglycaemia. V. Bulikaitė and A. Šeškevičius (2004) indicate that it is necessary to involve psychological preparation of family members into training programmes in order to develop independence of children by developing their health-related skills. The training programmes for children with diabetes must be active and inclusive, so that children could develop their awareness (understand the severity of their disease and know how to manage it) (Dobrovolskienė, 2008),

as well as motivated because motivation helps to achieve higher independence level (Bartkevičiūtė et al., 2015).

It should be noted that there were two regulated training programmes in Lithuania: Lithuanian Diabetes Association implemented a project *Management of Diabetes – Training of People With Diabetes Mellitus* between 2006 and 2007, as well as organised a continuing training programme – *Programme for the Management of Diabetes* between 2009 and 2011. The common goal of both programmes were to develop a unified system, which would be responsible for the initial prevention of risk related to carbohydrate metabolism disorders, prophylaxis of diabetes, improvement and practical implementation of the system diagnosing Diabetes Mellitus, improvement of control of people with diabetes in order to postpone the occurrence of complications, as well as improvement of treatment of complications experienced by people with diabetes in order to maintain their working capacities and high quality of life.

In summary of the above-mentioned training programmes, which are being performed in England, Ireland and Spain, it can be stated that the purpose of such programmes for children with diabetes is to provide health-related knowledge and skills, enabling them to manage this disease, helping them live a high quality life and to be independent and responsible for the condition of their health.

Analysis of research results
Competences of children with Diabetes Mellitus used to manage their disease

Diabetes is a tiring disease, involving not only a child, but his/her entire family. After falling ill, a child with diabetes has to change his daily activities and habits, to plan daily agenda and to manage the disease (American diabetes association, 2018). The parents and their child with diabetes require knowledge and skills, which would help them to manage the disease (Beran & Golay, 2017). The disease management is one of the primary aspects in order to avoid complications and to ensure much better health (Forlenza, Pinhas-Hamiel, & Liljenquist, 2019).

In order to disclose competences of children with diabetes, helping them to manage this disease, the respondents have been asked the following questions: "How do you manage or control your disease?" Having analysed responses of children, it was noted that the correct injection of insulin helps to manage the disease – *"Hm...well, how should I call it? An insulin... The injection of insulin... It is scary... And it's very painful... But it is necessary. My mother says that I have to inject it and that I have to learn how to inject it correctly, so I'm trying to learn..." (A), "I think that it is important to inject insulin correctly... That's true..." (C).* The foreign authors (Forlenza et al., 2019) emphasise that if a child

doesn't have an insulin pump, then it is necessary to learn how to inject insulin correctly and calculate its necessary amount because it helps to avoid both hypoglycaemia and hyperglycaemia. The respondents also emphasised that proper consumption of food also helps them to manage their disease better – "*Hm, I think that healthy nutrition helps a lot... I can't eat sweets... I eat everything sugar-free, although I really want it sometimes... Especially, during birthdays of my friends and mine... But when sugar level drops, I may eat a candy...*" *(B), "I eat vegetables... and certain porridges... In fact, my mother helps me... She observes what I should eat and what I should not... But I know that food is important..." (D).* The scientists (Thomson et al., 2019) note that proper and balanced nutrition helps a child with diabetes to feel good and it improves his/her health condition; therefore, it is very important to adhere to the assigned diet. Children, who participated in the research, emphasised that management of acute conditions (hypoglycaemia and hyperglycaemia) had an impact on the disease management – "*I feel weak when blood sugar level is very low... Then I feel dizzy and sick... I would prefer not to experience it. Therefore, I'm trying to prevent it...*" *(E), "Sometimes, there are.... Such conditions... How should I call them? Mom, how should I call them? Hypoglycaemia and hyperglycaemia... Yes, those ones... They are very nasty; therefore, I put all my efforts to prevent them...".* According to the foreign authors (Hendrieckx, Gonder – Frederick, Heller, Snoek, & Speigth, 2019) both parents and their children must receive medical and psychological help to prevent hypoglycaemia and hyperglycaemia conditions or, at least, to reduce their fear of them. The respondents indicated that self-knowledge, a timely recognition of changes in the bodily senses and immediate response to any changes are very important for the management of disease: "*You feel changes and reactions in your body... Eventually, you recognise those changes and know what to do" (D), "When I feel weak, I immediately take glucose tablets... That's how I manage it"* (C). Hence, awareness, self-knowledge, tracking of personal reactions and changes in the body enable children to manage hypoglycaemia and hyperglycaemia.

A child with diabetes has to develop self-reliance to live a complete and high quality life by taking care of oneself.

The scientists (Forlenza et al., 2019; Thomson et al., 2019; Hendrieckx et al., 2019) who analysed competences of children with diabetes to manage their disease, emphasised that injection of insulin, a balanced nutrition and management of acute conditions are the primary components for the management of diabetes.

Having concluded responses of research participants, we may see that children with diabetes distinguish the following four primary competences of disease management: the correct injection of insulin, proper consumption of food, a timely recognition of changes in the bodily senses and immediate response to

any changes, which enables respondents to manage hypoglycaemia and hyperglycaemia.

Conclusions

The purpose of the training programmes for children with diabetes, organised in such European countries as England, Ireland and Spain, is to provide the necessary health-related knowledge and skills, helping them to manage their disease.

There were two regulated training programmes in Lithuania: *Management of Diabetes – Training of People With Diabetes Mellitus*, organised between 2006 and 2007, as well as a continuing training programme – *Programme for the Management of Diabetes*, arranged between 2009 and 2011, which common goal was to achieve that people with diabetes would learn to manage their disease, receive the necessary health-related knowledge and skills, and strengthen the entire health system. During the training programmes it was observed that patients with diabetes mastered knowledge how to eat properly and how to take care of one's health status.

Based on the experience of children with diabetes, who participated in the research, it was found out that the following competences help them to manage their disease best: the correct injection of insulin, proper consumption of food, self-knowledge, a timely recognition of changes in the bodily senses and immediate response to any changes, which enables them to manage such acute conditions as hypoglycaemia and hyperglycaemia.

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